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## Living with HIV, from a transcultural perspective. A comparative study between Spanish and Swedish young.

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### Abstract

This study presents some results of a qualitative research about the processes of social exclusion experienced by a sample of Spanish and Swedish young, with HIV through horizontal transmission (sexual relations in all cases). The aim is to analyze the impact of HIV/AIDS in their social and personal lives and to identify and describe any cultural models circulating among them, relevant to processes of social exclusion, by focusing on the Cultural Consensus Theory. This research is based on the collection of autobiographical narratives of four young men between 26 and 27. While there is insignificant individual variability, there are also some common cultural and social responses to the stigmatizing power of HIV/AIDS in Spanish and Swedish youth culture.

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**Keywords:** HIV/AIDS; young people; culture; Spanish; Swedish; autobiographical narratives; Cultural Consensus Theory; stigma; exclusion.

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### 1. Introduction

According to the latest report published by UNAIDS (2014), since the beginning of the epidemic more than 78 million people have become infected with HIV (Human Immunodeficiency Virus) and 39 million have died of AIDS (Acquired Immune Deficiency Syndrome). In the case of young people, in the last year they were still living with this disease 4 million aged between 15 and 24 years (UNAIDS, 2014). The group of young people is one of those with greater vulnerability due to the presence of multiple risk behaviors, for that reason the age where the largest number of new worldwide cases occur is between 15 and 24 years (Macci et al, 2008; Tarazona, 2006).

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The increase of HIV/AIDS has become a social problem in which the adolescent and young community have become involved. HIV and AIDS have stopped being a problem for certain groups socially disadvantaged, to become a present threat in all social spheres, besides a constant risk for the youth group. In that way, thanks to the advance, models related to transmission prevention have included new perspectives insisting more on risk behaviors than on risk groups, from what has been called anthropologic-cultural approach (Estrada, 2004). However, specific practices are not being considered and the use of the condom as the only universal measure is being stressed without taking into account the specific characteristics of the different populations along with their language, cultures, expectations and motivations (Gasch & Tomás, 2014). HIV/AIDS is a complex phenomenon that emphasizes feelings, thoughts and behaviors proper of a particular group of subjects, in this case young people, located in a particular social and cultural context (Alvarez, 2004; Moscovici, 1998; Wagner et al., 1999).

Young people with HIV live the disease in a specific way but, generally, undergoing a variety of psychological reactions that are enhanced by the many uncertainties related to the emergence of symptoms, the period of transition from infection to disease, quality of life after diagnosis and so on. Though, these reactions occur in a social and cultural context made up of family, friends and colleagues; clinical experience and research reveals certain patterns of response in these patients: a shift from shock to denial, crisis, depression, guilt and panic to fight to find a sense of life, etc. Losses suffered by these people can be enormous: physical and mental health, energy, social status, career decision-making control, self-esteem, future expectations, personal relationships, financial independence, etc. (Despa, 2013).

For all that, HIV/AIDS is not only a medical or health condition, it is a social phenomenon which causes different behaviors, beliefs and feelings, mostly influenced by the social image of the virus in a specific cultural environment. As the United Nations Population Fund (UNFPA 2011) recommends, it is necessary a direct approach and intervention with young people because they are the base population of the nations and hence striving for their quality and psychological wellbeing is going to have a determinant impact on the society's future, and the possibility of its development (Posada, Rincón & Orcasita, 2014).

### *1.1. Objectives*

The main objective of this study is to know how young people, generally newly diagnosed, live with this infection (HIV). How they perceive their seropositive condition and its effects in their lives including changes related to the image of themselves and others (family, friends...), their relationships, expectations for the future, family and social support, and lifestyle, from the knowledge of the diagnosis.

Las but not least, there is a specific aim (resulting from a doctoral stay at the University of Uppsala, Sweden), which is to conduct a comparative transcultural study among Spanish and Swedish young, with a similar profile, to detect if there are similarities in their life experiences, despite their cultural differences.

### *1.2. Method*

This study has followed a descriptive method. According to Montero (2005), this methodology is characterized by describing populations without including hypothesis in its approach. Thus, we have examined independently autobiographical narratives or life histories, collected through semi-structured interviews from four young guys between 25 and 27 years, to integrate the discourse generated by the informants, in a second phase, in the analysis of the research object with the goal of obtaining an objective view of the reality to avoid possible biases that could potentially hinder the investigation process (Djik, 2005).

From the transcultural perspective, this study has taken as starting the "Cultural Consensus Theory" or Cultural Consensus Model. According to Susan Weller (2007, 339), this model aims to "estimate the degree of knowledge that individuals have about ideas and cultural beliefs. For this, the Theory valued culturally correct answers to a series of questions and at the same time, the knowledge of each interviewed or the degree to which each respondent share the answers".

### 1.3. Sample

Our fieldwork took place initially as part of a National Research Project (Ref. EDU2009-08923), in which I collaborated as technical researcher, and my Doctoral Thesis, in process, both of them related to HIV. During this first stage, between October 2010 and February 2013, 39 young and young adult (32 males and 7 females) aged between 19 and 42 years at the time of diagnosis, were interviewed at a major hospital in southern Spain. In a second stage, during my predoctoral stay in Sweden (September to November 2015), I could access to HIV-Sverige, a national nonprofit organization working with the goal of improving the lives of people living with HIV in Sweden. In this organization I carried out two more interviews to compare with two of the Spanish cases.

Both samples were non-probabilistic, giving a clear example of the specific characteristics of the current population of new cases (Hernandez, Fernandez & Baptista, 2010). This profile was young men, between 25 and 27 years old, who had had sex with men, from a high cultural and academic level (university studies in all of them).

### 1.4. Procedure

Although the research was carried out in two different countries and periods, the procedure was the same in both cases. Initially, we got the acceptance of hospital bioethics committee and the head of HIV-Sverige, in order to access its users. After that, participants were informed about the research process, the anonymity of their answers and the aims of the study. Following this, one semi-structured interviews took place with the consent of the boys, being performed by the lead researcher of the national project and me, in the case of Spain, and by myself in Sweden. In all interviews young were the primary but not the only one source of information. Data from hospital doctors and directors of the organization were also obtained.

Once this process was finalized the transcription and categorization of the data were done with Atlas. Ti 6.2 Software. Following this, the results of the project were noted, highlighting the analysis of the content of the data to, finally, held a discussion of the results using the Cultural Consensus Theory (Susan Weller, 2007), looking for the degree of agreement obtained from the four speeches in relation to a series of questions.

## 2. Results and Discussion

This section presents some results obtained from the 4 autobiographical narratives and its discussion. Generally can be perceived the same discursive line about how they live with the virus and how it has changed their lives, in all four cases, with a certain degree of agreement and a greater or lesser extent in all of them despite the different cultures.

The analyzed narratives reveal certain regularities in terms of common cultural competence among different people, without any relationship between them and from two different countries. Consequently, we can speak of a group of cognitive elaborations and common adaptive behaviors shared by relatively unsystematic and diffuse processes of cultural transmission, in relation to the main focus areas covered in the interviews: how they acquired the infection, their first reactions, changes in their social and personal relationships, changes related to their self-image, how to coexist with the disease, how conceal it and their future expectations, all after knowing the diagnosis.

There are many researchers that corroborate the relevance and remarkable impact of HIV in all these areas, as Cantú et al. (2012). Other, like Goodheart y Lansing (1997), lists other threats that can affect a chronic disease such as HIV/AIDS: threats to life and physical well-being; loss of independence, privacy, autonomy and control; decreased self-esteem and limitations in social participation; disorder in life projects; loss of relationships...

The autobiographical narratives of the sample interviewed reflect many of these threats, sometimes in an extreme degree. To continue, some of the main focus listed will be discussed. In order to facilitate its interpretation, will be used literal expressions from the interviews.

### 2.1. First reactions

Disorders that occur more frequently at the time of knowing the diagnosis are anxiety, fear, depression, states of shock or disbelief and, in some cases, behavioral disorders (Lester et al., 2002):

*"I had an anxiety attack [...] scared me a lot [...] I was unhinged. I thought I was going to die"* (Spanish young, 25 years).

*"Fear! I was in shock for some time"* (Swedish young, 26 years)

*"Feelings of guilt, stigma and rejection, breakups, dropout... I pushed through it. It hit me hard a year later on the one year day"* (Swedish young, 27 years).

Other of the first reactions observed in their speeches are denial and regret:

*"I said I could not be infected. That was a disease of drug addicts or people... You know. Ugly people, people with poor appearance and said, 'that cannot be'. Then, I paid for the test, I did it many times and all gave the same: positive [...] Currently, I keep looking in the mirror and saying 'Me? It is impossible that I can have this'"* (Spanish young, 26 years).

### 2.2. Relationships

A limitation in the relationship is evident due to the fear that HIV diagnosis is discovered or revealed (Iglesias, González & León, 2015). They realize that henceforth they cannot escape the possibility of infecting others, their partners, perhaps their children. And this responsibility overwhelms them, resulting in an immediate restriction of sexual activity and even emotional relationships, even when they already have a couple:

*"I was and still am in an open relationship. However, my greatest fear was that my carelessness had put him at risk. All else was at that time secondary [...] My sexual relations with my partner have been changed. He has an immense fear of HIV"* (Swedish young, 26 years).

*"My partner has still his HIV scare and it hampers us. But, I have to live with that"* (Swedish young, 27 years).

In other cases, this latent threat becomes unbearable and they give up all kinds of relationships:

*"For a long time I did not want anyone to kiss me or touch me... I always had fear and I thought 'if I have acquired the infection despite all caution, it can be transferred to another person even with the caution and I cannot do that'"* (Spanish young, 26 years).

### 2.3. Self-image

If HIV infection progressively destroys the immune system of the individual at the same time destroy his psychological immunity, giving rise to a variety of negative feelings: guilty feelings, anger, uncertainty, despair, distrust, shame, disgust (Despa, 2013). All this affects their self-image:

*"I felt dead, or as a walking dead for some time"* (Swedish young, 26 years).

*"I know that I'm right outside, but inside not. I know that's something that is there and I have to live with that"* (Spanish young, 26 years).

Respondents believe the disease has made them to mature and become aware of the most important aspects of life:

*"I've matured a lot. You learn to appreciate everything. I remember that in August took vacation and got to the beach and breathed in the sea and it smelled different from last summer, it gave me more life [...] You think about how small we are, right? How insignificant..."* (Spanish young, 25 years).

*"To some degree I think it have to do with my realization that I will die one day. That have made me care less about worldly things"* (Swedish young, 27 years).

In the same line, there are also changes in the way of seeing to others:

*“It has greatly changed my way of seeing other people. The first day I came here there were drug addicts who were out waiting to give them an appointment and for me, before having the infection, it was like ‘what dispossession of society!’ Now I think I do not know the circumstances of life of these people and I even feel sorry and compare myself with them and think that maybe they also have the infection like me”* (Spanish young, 25 years).

#### 2.4. Concealment

Another fundamental aspect to take into account is the need to prevent the social exclusion and rejection attached to the disease. This is what they most fear. In that way, in all four cases hiding rituals are observed as a part of a big strategy of concealment, in order to prevent others discover the seriousness of their condition (Swaans et al., 2009):

*“I have everything in my house kept in a cupboard which nobody touch”* (Spanish young, 26 years).

*“I have like a box at the top of the headboard and there I keep pills and pill boxes and put over hand cream, Vaseline, phone charger... So I cover everything”* (Spanish young, 25 years).

*“I have my pills hidden in sight, so I never forget them, but others don’t get that is inside the box”* (Swedish young, 26 years)

*“We call my pills for vitamins, and the interest group PGsyd for vitaminclub [...] I hide my pills in an empty box for eye-glass wipes. It fits perfectly”* (Swedish young, 27 years)

Other element of this strategy of concealment is to minimize the social circle of trust, committed to the proposition that the disease should not be disclosed to people beyond a small circle: doctors, some family members and, sometimes, a limited number of friends. In that sense, silence and secrecy grow in importance in the lives of these youth:

*“Only my mother and my brother because he found an analytic. My sisters and my father don’t know it. My brother gave me his support, he was informed about the disease and offered to come with me to the doctor. However, my father would make me feel guilty. So, I’d rather he doesn’t know it”* (Spanish young, 26 years).

*“My sister is the only of my blood kin that know, my sister and I both agree that our parents and brother can’t handle it”* (Swedish young, 26 years).

The fear that their secret may be revealed at any moment compels them to engage in evasive behaviour; they feel uncomfortable with other because of this and end up leaving for fear of being found out and rejected. Though this involves loss of the company and support that friends and family can provide (Pérez, 2006), sometimes they prefer don’t disclose to anyone their status:

*“I have not told any friends [...] I do not want to hear rumors where I go”* (Spanish young, 26 years).

*“Neither my parents nor my sister. No one knows. Only two of my friends”* (Spanish young, 25 years).

The adoption of these strategies of deception, containment and isolation, can cause them certain social conflicts related to determined coping behaviors of the disease (Fleishman et al., 2000).

#### 2.5. Future expectations

To conclude this section, among the major disruptions that can occur in people with HIV we also found changes in their life expectations and the way of thinking about the future (Ortúzar, 1995). Knowledge of diagnosis often triggers a nervous breakdown, which makes them think they can not comply with their projects:

*“[...] at that moment I was blocked because I had planned to go to Madrid, I had many projects and they all disappeared [...] It has removed me the ability to go out”* (Spanish young, 26 years).

In other cases, after going through a phase of uncertainty, the disease has taught them to consider the future in a different way. They prefer to make the most of the day and focus on the future with the greatest possible realism:

*“I can get stressed over inefficiently use time. I do thing more directly now. Less time for bull shit”* (Swedish young, 26 years).

*“I intend to find something meaningful to work with, I have done that. I am a teacher now. I will perhaps tart to be more active in politics, while I can”* (Swedish young, 27 years).

### 3. Conclusions

As a final conclusion, it should be noted that although this study doesn't aim to generalize about the entire Spanish and Swedish youth, by the limitations of the sample, from analysis is perceived that the life experiences of these young do not differ significantly despite belonging to different cultures, reproducing very similar patterns among them.

The condition of individual and biographical narratives doesn't diminish their cultural significance. That's why we have interpreted it from a comparative perspective, to seek and find in them, by using the analogy, cultural knowledge, i.e., shared meanings about how young people live with HIV and how it has changed their lives.

These autobiographical narratives also have an invaluable clinical, psychological and educational value, as they are testimony born from the personal experience, as from which we can develop projects and educational interventions for young people in general.

Regarding to HIV, there is an evident smokescreen created in relation to the real problems seropositive people have; the consequences in their lives or their needs are not evident at all (Fernández-Dávila, 2007).

Agreeing with Despa, (2013), the most serious problem that faces people with HIV/AIDS is the fear to the discrimination and social stigmatization that the infection represents. Stigma and discrimination associated with HIV have led in many cases the social marginalization of those infected and they also generate their self-exclusion caused by this fear to be rejected. This is in line with the issues raised by authors such as Orcasita, Peralta & Valderrama (2010) or Gomez (2008) who speak about the young's fear of disclosure due to stigmatization and judgment values. As a result, they often feel excluded just when they most need help and support.

The image of people with HIV in most societies, even from different countries as in this study, is too altered. This discrimination against because of the virus is associated, most times, to behaviors that are considered deviant, particularly homosexuality, prostitution and injecting drugs (Despa, 2013). Definitely, false social prejudices that still exist in our times and can give rise to terrible trauma, both physical and social.

To end, and in regard to the importance of the support networks, friends and family are some of the networks that are reduced by the mistrust to disclose the diagnosis and the scare of transmitting HIV in a sexual encounter. Accordingly, it is necessary to work to strengthen the structure of these networks, so that young know the care they should take with their new seropositive condition, the actual possibilities of transmission and the social myths about the disease. From a holistic approach to health and the disease, it is important to involve these networks and the health institution as well as the peers and partners, in order to promote this view of the subject from its potential and capacity as it is, which contributes to the perception of HIV as a condition of life that can be taken from an active and purposeful position (Posada, Rincón & Orcasita, 2014).

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